PERFORMING PREVIVORSHIP ONLINE: EXAMINING IDENTITY MANAGEMENT ON TIKTOK

Hannah Ditchfield
University of Sheffield

Stefania Vicari
University of Sheffield

With the growing popularity and prevalence of Tiktok as a social media platform, scholarship has tended to focus on the "distinctive technical structure" of the platform (Zulli and Zulli, 2020, pg. 1872) and particularly in the role of the ranking algorithm in shaping content, connections and experiences of this particular online space (see Avella, 2023; Klug, Qin, Evans and Kaufman, 2021; Krutrok, 2021). This focus has led to less attention being paid to the ways in which identity is performed and managed on the platform.

Work that has conceptualised identity performance on Tiktok has again highlighted the role of the algorithm arguing that we are departing from older self-making frameworks - such as the networked self- and are instead moving towards a more 'algorithmized self' (Bhandari and Bimo, 2022). This departure moves us from a framework that emphasises user agency, creativity and performance in the Goffmanian sense to a model that emphasises the role of the algorithm in shaping our self-making practices. This paper extends work that conceptualises identity and self on TikTok by further exploring the extent to which we may have departed from older self-making frameworks. To do this, we look at how active content creators, rather observers, work to perform their identities in particular TikTok spaces, specifically in the context of health and illness.

Social media platforms have been established as important spaces for the performance of both health and illness identities (see Tembeck, 2016; Kent 2020). Tembeck, for example, has highlighted how platforms offer a space for authopathographic performances where users can engage in self-representational practices (such as selfies) to display experiences of illness and "come out" as "visibility ill" (2016, pg. 1). Despite the distinctive technical structure of TikTok, and the move towards more

algorithmized selves, this paper asks whether and how illness performances occur on this platform, especially in relation to illnesses that remain largely invisible.

To address these questions, we draw on findings from an ongoing Leverhulme Trust-funded project focused on social media uses relevant to hereditary cancer syndromes. These syndromes mark health conditions linked to known genetic mutations, also called "cancer genes", that heighten the risk of having cancer from an early age. conditions are *invisible* in at least three ways: 1) cancer genetic risk is evidence-based and embodied, but not bodily visible 2) general health practitioners rarely know about hereditary cancer syndromes and 3) overall, hereditary cancer syndromes have not yet entered the wider collective imagination. Carriers of these genetic mutations are often referred to as 'previvors': healthy individuals who are coping with the awareness of having a genetic predisposition to cancer and who are often faced with choices around preventing, or lowering, their risk e.g. through constant screening or in some cases preventative surgery.

In line with research on illness identities, genetic risk management and responsibility have been investigated as embedded in new forms of subjectivity and selfhood (see Ross, Kerr, Cunningham-Burley, 2018 and Hallowell and Lawton, 2022). These involve the renegotiation of one's social relationships to accommodate risk-derived uncertainty in everyday life and are central to the emergence of new individualities. In other words, the awareness of carrying a genetic mutation affects how we construct and perform our identity. Existing research provides clear evidence that individuals with these conditions turn to social media to seek, learn, produce and share information and stories about their condition (Allen, Roberts, Anderson and Khoury, 2020; Wellman, Holton, Kaphingst, 2022) however less is known about how they manage, and perform, their identities as previvors in these spaces.

Data and Methods

To fill this gap, this paper draws on the collection and analysis of TikTok content relevant to two hereditary cancer syndromes: BRCA 1/2 and Lynch Syndrome. Drawing on existing conceptualisations of digital methods for cultural research (Vicari and Kirby, 2022) we used computational techniques and tools to access, collect and handle posts (i.e., data and metadata) about these conditions published on TikTok. We then conducted a qualitative content analysis of 100 posts published in March 2023 by both BRCA and Lynch Syndrome previvors. Following approaches laid out by previous Tiktok research (e.g. Ebbrecht-Hartmann and Divon 2022 and Krutrok, 2021) we constructed a coding schedule that allowed us to identify the kinds of identities that previvors create and perform in posts that use #brca and #lynchsyndrome. This was followed by conducting a closer textual analysis of 20 of the 100 posts collected. This paper approaches activities undertaken on social media "as not merely reflective of the everyday presentations of self that occur offline" due to the specific affordances that platforms offer to users (Tembeck, 2016, pg. 3). Because of this, we also coded the communicative features that previvors use and engage with in their Tiktok content to gain a more comprehensive understanding of *how* previvors perform and manage their identities online.

Preliminary findings

Despite arguments that self-making is departing from older frameworks based on the networked self and identity performance, our initial findings show how strong elements of this are still present in content produced by previvors on Tiktok. We found previvors to perform various types of identity within their online content ranging from being 'the friend' to 'the educator' to 'the defender' in which previvors performed more politicized identities when justifying their decisions on managing the risk of their conditions. We also found that previvors identity performances are still very much networked, interactive and connected to specific communities. This is especially prevalent in content that mimics interactions, addresses specific questions from fellow previvors or that involves collaborations such as through the 'duet' function of the platform. With these findings, this paper contributes to scholarship working to understand the relationship between social media users, platform structures and identity management with questions being raised around the amount of agency previvors, but more broadly Tiktok users, have when it comes to 'self-making' on this platform.

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